Journal of Mental Health

On being a girlfriend not a patient: The quest for an acceptable identity amongst people diagnosed with a severe mental illness

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On being a girlfriend not a patient: The quest for an acceptable identity amongst people diagnosed with a severe mental illness

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Abstract

Background: Whilst the ways in which mental illness influences personhood have been documented, how social support can forge a more positive identity has not been explored.

Aims: Using Goffman's theories of stigma the aim of this paper is to report on a qualitative study of how 17 people diagnosed with a severe mental illness received and provided social support in order to forge and manage a less stigmatizing identity than that of "being sick". Courtesy-stigma as an issue for those trying to live "ordinary" lives is highlighted.

Method: Qualitative research methods were used including unstructured open-ended interviews.

Results: Individuals reported that social support could be helpful in terms of developing a more "acceptable" identity, which enabled some degree of social integration into mainstream life. On the other hand, people who managed to "escape" from lives defined by their mental health status, sometimes found life on the outside stressful and rejecting. This led to some seeking refuge in the mental health community again.

Conclusion: Social support plays a vital role in the construction of a more valuable identity than that of patient.[1]

Declaration of interest: The Sainsbury Centre for Mental Health sponsored the research.

Keywords: *Mental health, courtesy-stigma*

I'm going out with him, I'm a girlfriend, he gives me support and I give him support.

Introduction

Identity as a concept has a long history (see Becker, 1963; Erikson, 1956; Guiot, 1977; McCall & Simmons, 1978) and has continued to be of central importance to the understanding of the sociology of health and illness, in particular mental health (see Barham & Hayward, 1991; Barton, 1959; Cotterill, 1994; Estroff, 1985; Goffman, 1959, 1961, 1962; McCourt Perring, 1993; Scheff 1966). Within the symbolic interactionist perspective, identity is defined as the construction of one's own sense of self. Identities are forged by the social situation in which a person finds themselves and how interactions with others relate to

that person's self-concept (including self-esteem, self-image and self-evaluation). A process of negotiation, bargaining (Blumstein, 1973) and reciprocity (Gecas, 1982) takes place for identities to be formed, changed or maintained and people will present themselves and act in particular ways during social encounters (engaging in "impression-management", "face-saving", and "alter-casting" (Goffman, 1959, 1962)) in order to create or "win" the most socially situated and desired identity available to them (Alexander & Wiley, 1981). Within this interactionist perspective, labelling theory suggests that society's reaction to an individual's behaviour alters the social identity or internalized roles of the person labelled (Lemert, 1951).

Goffman (1962) showed how formal labelling (e.g., arrest or imprisonment) and informal labelling (e.g., stigmatization of people with mental health problems) led to diminished self-concepts and identities. In an attempt to rid themselves of stigmatized labels, people will engage in "resistance to labelling" (Prus, 1975) by taking on other, more acceptable roles. On the other hand, if the label is useful or if relationships with others are dependent on it (Stryker, 1968) or there appears to be little chance of shaking it off ("deviant labels are sticky" Goode, 1984, p. 35) a person might engage in behaviour which fulfils the prophecy.

Studies on psychiatric stigma have tended to focus on how general public attitudes and stigmatizing behaviour (hurtful media representations, patronizing attitudes and being rejected) causes difficulties to individuals with mental illness (e.g., low self-esteem and identities of deviance) (Schulze & Angermeyer, 2003; Wahl, 1999). Prior (1993) drew on the work of Goffman (1961) to reassess the impact of institutionalization on the identity of psychiatric patients. Similarly Lester and Tritter (2005) explored the impact on individual identity of living with a mental illness within a society that still largely perceives people with serious mental illness as "other". Whilst Link et al. (1999) hypothesized that "secrecy" and "withdrawal" were relevant strategies for people who are mentally ill and/or use drugs, studies have hitherto overlooked patient's subjective everyday experiences of, and attempts at managing their stigmatized identities through their social support networks (Lee et al., 2005).

By using Goffman's theories of stigma and stigma management the aim of this paper is to report on a study exploring how people with mental illness try to negotiate more acceptable identities through their social relationships. Through their own narratives, study participants show how social support given and received can assist in constructing a valuable sense of who they are and where they fit in their local community, leading to more highly desired social identities other than "mental health patient". Study participants also describe how some social relationships provide support which is either not asked for or not wanted and which can help maintain undesirable identities characterized by stigma. To this end, the following research questions are addressed:

- What identities (acceptable or otherwise) were available to study participants?
- What were the influences on the construction of these identities?
- How did the presence or absence of social support move participants towards a more acceptable personal identity?

Furthering our understanding of the importance of social support to perceptions of illness and identity is therefore at the heart of this paper.

The study participants had all experienced de-institutionalization (during 1989–2000) as an outcome of Government Policy (DoH, 1990), which led to an increase in the visibility of people with severe mental illness in local communities, especially in small seaside towns,

which had been targets for resettlement officers due to the decline in tourism during the 1970s–1980s.[2] Accommodation was plentiful and relatively inexpensive compared to the cities, and in some localities, resettlement programmes were well resourced (Leff et al., 1996). However, within care packages, few considerations were made as regards to social networks. This was despite clear signs from studies (e.g., Forrester-Jones & Grant, 1997) indicating that people with severe mental illness had fewer social contacts compared to "ordinary" populations and network members were almost exclusively other people connected with mental health services.

A purposive sampling strategy was utilized since the study group ($n = 17$) had previously been part of a larger research cohort of 45 individuals studied by the Sainsbury Centre for Mental Health into the effectiveness of Intensive Case Management (Ford et al., 2001). Ethical committee (East Sussex Health Authority) approval was granted for a qualitative study into social support with a smaller sub-sample. All the participants had a diagnosis of severe mental illness, allied to a lengthy history of contact with psychiatric services, (over 20 years for the majority). Five individuals had criminal records, mainly for petty offences committed whilst out of contact with mental health services. Five of the group were women, all but one were over 30 years of age, with three being over 60 as shown in Table I.

When asked the question "who do you get support from?", the following network membership categories were identified by 16 participants: family, partner, other service users with mental health problems, residential carers. Participants were also asked who, out of those mentioned above provided the "most social support". Principle supporters identified by individuals were then contacted. Thirteen interviews with "principle supporters" were carried out (see Table II noting that some people were interviewed regarding more than one participant).

Table I. Participant characteristics.

Pseudonym	Gender	Age	Ethnic origin	Diagnosis	Admissions (no. of)	Admissions > 2 yrs y/n
Simon	M	43	White	Schizophrenic psychosis	7	No
David	M	48	White	Paranoid schizophrenia	11	Yes
Sarah	F	38	White	Affective personality disorder	8	No
Michael	M	51	White	Manic depression/mild learning disability	3	Yes
Stuart	M	64	White	Affective psychosis with manic episodes	15	No
James	M	51	White	Schizophrenic psychosis	6	Yes
Tony	M	55	White	Chronic schizophrenia	2	No
Graham	M	42	White	Affective psychosis with manic episodes	15	Yes
Andrew	M	63	White	Chronic schizophrenia	4	Yes
Mary	F	57	White	Chronic schizophrenia	7	Yes
Roy	M	66	White	Chronic schizophrenia	10	Yes
John	M	61	White	Schizophrenia	8	Yes
Frank	M	56	White	Schizophrenic psychosis with learning difficulties	5	Yes
Darren	M	38	White	Affective psychosis	10	Yes
Jane	F	50	White	Chronic schizophrenia	6	No
Sophie	F	57	White	schizophrenia	6	Yes
Angela	F	38	White	Paranoid personality disorder	0	No

Table II. Interviews with "principle supporters".

Network member	Number of interviews
Friend/family with mental health problems	3
Day centre manager	2
Case manager	2 (talking about 6 participants)
Community Psychiatric Nurse	2
Residential homeowners	2
Accommodation Officers	2 (talking about 3 participants)

Method and analysis

An ethnographic approach was utilized. Apart from reflective fieldwork notes, data was collected using personal narratives, focus groups, one-to-one unstructured interviews, naturalistic conversations and participant observation of individuals' interactions in various group settings (e.g., acute wards and pressure group meetings). Such methods enabled the study participants to emerge as people, agents in their own destiny. Such a model of subjective reality is phenomenologically oriented, it accepts multiple realities and is regarded as "no less real than the objectively defined and measured reality" (Fetterman, 1989, p. 11). A latent thematic analysis (Field & Morse, 1991; Strauss, 1967) was carried out on transcribed data. Text was systematically reviewed within the context of the passage in order to identify and code major significant theoretical categories and themes. A computer software programme (NVIVO) was used to assist in coding. Comparative methods of Glaser (1992) were utilised in this process including comparing different people's accounts and experiences, comparing data from the same individuals with themselves at different time points, comparing data with categories and refining and re-defining categories. Further collected data either falsified or corroborated categories with natural themes generated. This emerging framework was tested and re-tested independently by both authors and there was a very high degree of agreement about the themes. This inductive, analytical process (Glaser & Strauss, 1967) enabled a theoretical framework to develop which explained the data. At it's highest form, theoretical models of "availability of acceptable identities" were generated (see Figures 1 and 2).

Ethical issues and limitations

Since the fieldwork was protracted over a number of years, the participants became known personally to the researcher, and it would be unrealistic for this not to have affected the research. Some individuals became more like friends than others, despite attempts to treat everyone in an even-handed way, and with the best will in the world, neutrality was sometimes compromised, arguably resulting in data limitations. Moreover, sometimes there was an uncomfortable feeling of voyeuristic exploitation towards participants. How far were people really offering free consent to be research participants? What sort of research bargain was being struck? Issues of power, financial advantage and career progression beset the research process. Many individuals interviewed experienced exclusion from the labour market and resultant poverty, particularly those living in residential care. The NHS Support Unit advocates payment for research participants if they are otherwise unwaged (Hanley et al., 2000) and whilst not common practice at the time, study participants were paid expenses to attend interviews. In order to move someway towards resolving power differentials, a policy of mutual exchange and self-disclosure was adopted.
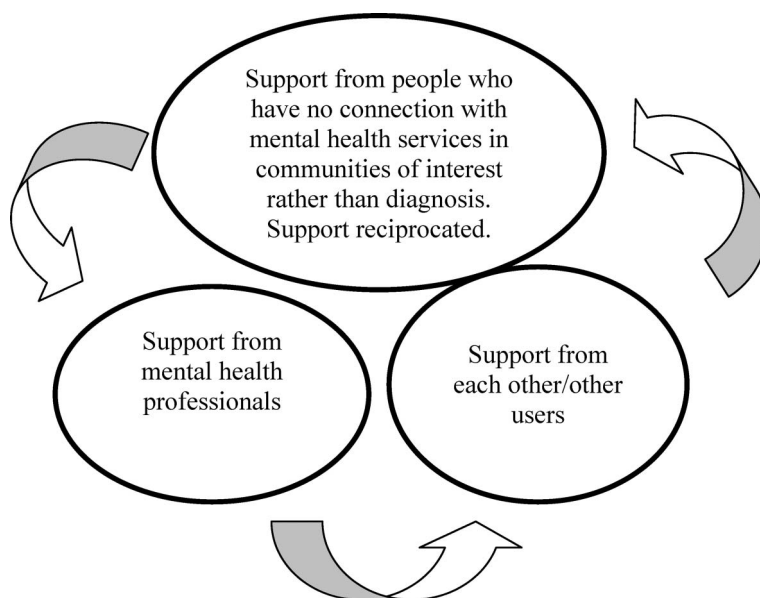
Figure 1. A model of social support.
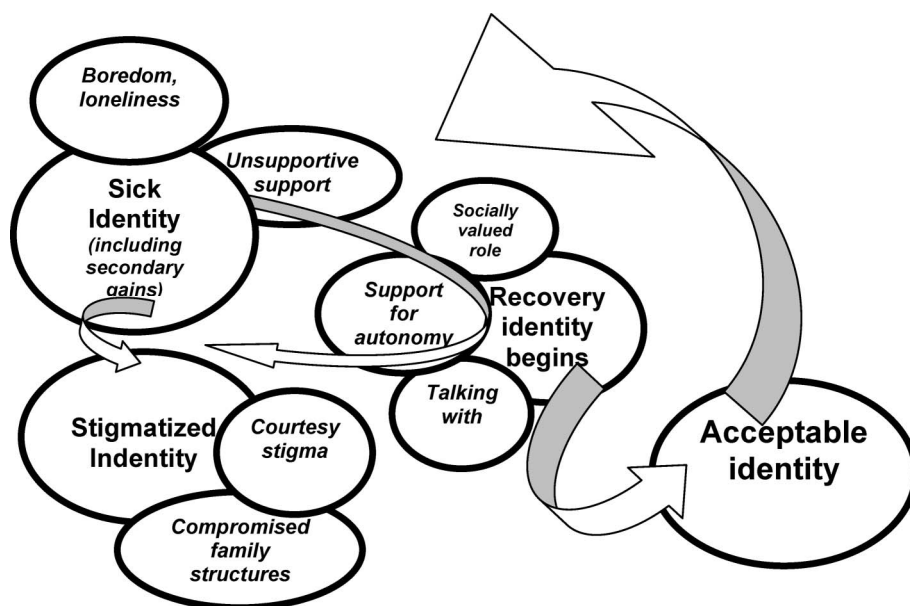
Figure 2. A model mapping the consequences of support in relation to identities.

Discussions about what had occurred in each others' lives since the previous meeting, took place at the beginning of each interview. Once this part of the conversation was over, a conscious move was made towards a more professional research relationship in which assurances of confidentiality were re-iterated, such as anonymous data recording. This informal approach became more important as the richest material came from the simple

question "how have you been?" which generated participant-based narratives stretching back over 10 years.

Findings

A range of participant identities were generated from the data set including: "sick", "stigmatized", "recovery", and "acceptable". Re-occurring themes helping to explain these identities are described below.

The "sick" identity

All 17 participants recounted that being "sick" was part of their everyday existence and identity. Facets of the "sick identity" included feelings of de-motivation, inability to work, hopelessness, low self-esteem and passivity (also found by Gara et al., 1987). Individuals also had difficulties with symptoms of medication and physical functioning especially when living alone. The pen portrait of David from field notes and a quote by Sarah exemplify these:

> David . . . talked about politics, mental health policy and animal rights. His diagnosis was schizophrenia. At interview he expressed regret that he had not fulfilled his academic potential, had not sustained employment or experienced family life. David seemed to panic whilst living alone, and was frequently admitted.

> I find that well . . . I get depressed and it winds me up and I get miserable and down all the time. Like an extreme example of that was when I was in hospital, I found that really wound me up, as there were two bad things about it, one was too much medication, and the other was mixing with the other people that were really disturbed. (Sarah)

The "sick identity" was found to be influenced by a variety of social interactions as follows:

Unsupportive formal care. Individuals felt that professional care was often delivered in a way which undermined their sense of self-esteem and autonomy, and which was instrumental in constructing a sick identity, as highlighted by David who was living in a hospital at the time of this interview.

> I just don't like the idea of people being imprisoned because they are mentally ill, this whole thing about dangerousness, I mean you can get hold of anyone and you can sort of listen to what he or she says and you can say oh, he or she is dangerous we've got to section them and we've got to give them this drug or that drug and I just don't agree with it, I tried to take action over what happened to me when I was sectioned. (David)

David perceived professional support provided to him as clinical, labelling and pejorative and that a "stereotype threat" of "dangerousness" by professionals led to his forced hospital admission. Darren also found that help offered by services was not always supportive or wanted as indicated below:

> I went to 73a [day centre], on and off, for about one and three quarter years, but I found that as I was so well, I was able to cook for myself, and I was living in a stable home, in this

new home here, I moved in here five years ago, so I didn't need the social support they offered any more, and I found neither my wife Maggie or I smoke or drink or anything, and I found the smoking down there got on my nerves, I didn't like that, and some of the people were rather aggressive. I didn't feel very comfortable down there, a bit sort of threatening. (Darren)

This quote also illustrates how, as some individuals moved towards a self-concept of being well and independent, they wished to move away from segregated settings and people who engaged in behaviour at odds with the ''normal'' identity they wished to attain.

Boredom, loneliness and lives devoid of meaning. Fourteen participants reported that they became ''bored'' whilst recovering, and put their ''normal identities'' and health at risk through either criminal activity, or through manipulating their medication as discussed below by Jim, an informal carer talking about David:

Yes, he certainly likes that feeling [of being high] and manages his medication at times to bring that on because he doesn't like being flat and being organised, although there are probably more constructive ways that he could find excitement... (Jim)

During such periods those with little capacity for independent life were the most dependent on mental health services and networks. Below, Sophie discusses how loneliness, more than symptoms of mental illness, made her want to return to hospital. Her need for company was corroborated by Hazel, her care manager:

It's strange [living in the hospital] compared to here . . . . . I make the best of it. I could do with going into hospital to see people again. (Sophie)

I think there's a longing for um, you know, actually 'I'm missing seeing so and so' and then she [Sophie] misses medication and starts to become [unwell] comes in, sees people, starts taking the medication again, feels better, goes home, so now that she's becoming less ill less often I think there will be almost like bereavement because she will be missing those people.

Seven other individuals who lived alone also reported that periods in hospital provided much needed company. This was the most commonly expressed regret about the loss of the old institutions:

I quite liked Hellingly. I had a good time there. I was a grass cutter. We cut the grass in church yards all over East Sussex, and went to the pub every lunch time . . . I had an affair in Hellingly with Hazel. Those were the days. (Tony)

Forrester-Jones et al. (2002) and Lester and Tritter (2005) also found that care in the community equated with a solitary existence and boredom, especially during the evenings and weekends. Similarly a recent survey of over 3,000 people with severe mental illness (Rethink, 2004) found that even among those having contact with support organizations, a quarter had no or very little involvement with community activities on a daily basis.

Secondary gains of the sick identity. Apart from companionship, secondary gains of the "sick identity" included finance and abdication of responsibility.

Financial. Participants reported financial advantages of hospitalization since benefits claimed were not spent on domestic bills. This was not lost on paid staff who sometimes felt that individuals were "cashing in" on being ill, as illustrated by a case manager below:

> Last time he [Graham] was in [hospital] he saved up for a washing machine . . . we think he's in it this time for a tumble-drier.

This rather apocryphal story expresses that, despite their dislike of hospitals and incarceration, individuals gained something from admission. It also highlights how the stigma of being mentally ill re-surfaces. In any other context being able to save for a household appliance would be regarded as good business sense.

Relief from responsibility. Abdication of responsibility from daily life was a theme that emerged in three interviews with participants as illustrated by Emily, a carer-client talking about Sarah:

> Emily: . . . she'll get ill and won't have to deal with what she's got to face. She doesn't like dealing with things at all. If someone else can go and pay a bill for her, she'll let them. It's like, 'if I don't take my tablet I'll get ill and I won't have to deal with it' and that's what happens.

This quote also indicates important sub-cultural issues involved in being sane and insane. People with mental illness, far from being passive victims were apparently making a choice to opt out of life by letting themselves become ill or at least reverting back to a sick identity.

The stigmatized identity

The stigmatized identity was found to be linked to themes of personal presentation, compromised family structures and courtesy stigma. Unlike the more personal sick identity, the stigmatized identity was constructed by others without mental illnesses. Compared to the sick identity, few gains were to be made when stigmatized.

Personal presentation. More liberal views concerning appropriate dress, coupled with a fear of being pejorative have resulted in a tendency for recent studies (e.g., Cambridge et al. 2003) to shy away from using structured personal presentation checklists (e.g., Personal Presentation Checklist; Hampson, Judge & Renshaw, 1984). Nevertheless, ethnographic studies of people with mental health illnesses (Estroff, 1985; McCourt Perring, 1993), have shown that poor visible presentation of self including "personal hygiene, maintenance of clothing and wearing clothes properly" (Forrester-Jones & Grant, 1997, p. 103) is aligned to stigmatization and social isolation. In this study, all but two of the participants were noticeably unkempt in their appearance as shown from the following pen portrait notes:

> Simon was a middle aged-man with a wife and daughter from his previous life. He appeared untidy, poorly dressed with longish curly hair.

Sophie paid little attention to her appearance and habitually wore rags and wellington boots.

John refused to wash or clean clothes, preferring to wear one outfit at a time until it needed replacing, then taking it off in a charity shop where he would collect a new one. John was a distinctive figure in town. He talked loudly and incessantly to himself as he walked about.

That these people "refused" to adhere to so called normative appearances might also be indicative of their active construction of their own identities and a refusal at some level to conform to a "normal identity". In a quarter of the interviews with mental health professionals, visible presentation of self and home was a constant source of tension for formal or informal carers, as can be seen as follows:

On one visit I found it very disconcerting. I sat in the armchair and I felt something move and I said "oh, I didn't realise you had a cat" and she [Sophie] said "no, there are mice nesting in the armchair". Then on another visit I saw a rat walk along the kitchen and get up onto the table, and onto the cooker and walk across the frying pan, and it left its footmarks in cold fat...and she's only ever worn one jumper in the past 14 months and I don't know whether she had it on when you were there but I mean it was absolutely 'rank' and yet she's got two bags upstairs of clothes. I gave her a navy blue skirt with little yellow flowers on it and a navy blue jumper and every time I've been out there she's had that on. What it's about I think is that there's so much going on in her head that she doesn't focus on external things, and she can't. (Hazel, Care Manager)

Eight professionals said they missed the function played by the old hospitals in ensuring a stable and controlled life for their "clients", particularly in relation to personal hygiene. Both formal and informal carers stated that those they cared for had problems with personal and domestic issues, as described below:

When things got too bad the troops would come in, so to speak, and help James, help him tidy it all up... (informal carer)

He [Tony] needs control in certain areas, like making sure he bathes, or gets out of the room so the girls can clean his room, or shaves. (Residential homeowner)

Lack of attention to personal hygiene was therefore not acceptable to formal carers in terms of participants' ability to secure a stigma free identity. Whilst formal representations concerning what is acceptable within society have apparently been eroded, in reality, the social construction of and adherence to societal "normative" behaviour, which includes personal hygiene, is important in terms of "fitting in" with the rest of society.

Compromised family structures. Participants felt that social support provided by families was paternalistic, characterized by close monitoring and supervision. Individuals felt uncomfortable about these relationships which debilitated and reduced them back to child-like dependency, as exemplified by Joe who was a carer with a mental illness: "people who are well sometimes prefer it if you remain dependent on them". House et al. (1988) suggested that individuals can perceive social support as a form of social control which can

emphasize the stigma of dependency created by the sick role (McCourt Perring, 1993). Another participant, Michael who lived with his mother, father and older brother was almost completely controlled by his family, as revealed through researcher field notes:

> Michael's family talked loudly about him, literally speaking over his head to me, as he lay on the sofa. During the course of several interviews over 5 years I saw Michael become less and less ambulant, and more withdrawn. He seemed sunk in a deep depression, and communicated very little. His family answered my questions for him . . . his family income depended on his benefits and various attempts had been made to move him away from the family. They were never successful as they had intervened and brought him home.

Apart from Michael, all participants had experienced the loss of, or in some cases abusive interaction with family members, and this was a source of consternation to them. For example Simon had a wife and daughter whom he had lost contact with, and Sarah had lost custody of her son. Mary had been married but talked about being repeatedly abused by her husband. Jane was caring for her partner who had severe mental health problems and who had recently disappeared from the area. Sophie lived with her husband but had been unable to care for her children. One had therefore been educated at boarding school, the other she lost to local authority care. Individuals lamented the loss of contact with family members and were inadvertently stigmatized by professionals and informal carers who regarded this as symptomatic of their illness, despite the fact that wider societal family breakdown is not extraordinary. Emily, an informal carer talking about Sarah sums this up:

> When she's ill she doesn't want nothing to do with her mum, and mum don't want anything to do with her. Patrick [Sarah's father] can't cope with it because he's getting old anyway now so basically it is down to me and I've got 3 kids as well and a husband so it takes it's toll. . .

Similarly, Jane recounted having to call the police from a call box when her partner became mentally ill and started threatening her:

> Jane: I help him. Otherwise he'd keep walking like he used to . . . I once had to call the police because he had a knife . . . well he had to know it was wrong.
>
> I: How did you do that, have you got a phone?
>
> Jane: No I haven't, I just ran down stairs and up to the pay phone. They [police] were very good and helped me a lot with him. He needs money, food . . . I helped him move into his own place but he runs out of money all the time. How they expect us to manage on this money I don't know.
>
> I: Would it be easier if he lived in residential care do you think?
>
> Jane: He couldn't bear that, it would be like prison to him. He's a country boy, he needs the open air. I can look after him.

Families therefore had problems coping when their loved ones became "ill". This is part of the stigma of mental illness, the perceived burden their informal carers have to bear.

Courtesy-stigma. Whilst carrying a stigma can be very difficult, Goffman argued that people with shared stigma can at least provide each other with a ''circle of lament'' to which they can withdraw for moral support. This is exemplified by James talking about his fellow ex-patients:

> They know what the score is. Susan understands and the patients. I mean, we've been through a common experience together. We understand the system, we commiserate with each other.

And Susan talking about James:

> I think this is James' particular gift. James has got amazing insights, like when I was flapping and going into crisis about the ceiling falling down, James said quite rightly, look at all the predicaments I'd come through, this was just a temporary nuisance, and that this would resolve itself and be in the past. He put it in perspective. . . James has very valuable insights.

However, whilst being compassionate towards their colleagues, when their symptoms were least apparent, individuals chose to live their lives with people without mental illness as described by Mary who wished to be ''independent'' of other ''service users'' and James who felt he did not have the same problems as his contemporaries:

> You see I'm getting older, and the illness is dying down. I'd like to get a little flat eventually and settle down there . . . (Mary)

> I'm quite intelligent and others particularly on the ward . . . tend to develop an in-crowd of patients, it's a clique of friendship formed among the least disturbed patients . . . but I'm not in the in-crowd myself . . . (James)

Angela, who ''felt well'' and lived at home found it difficult to cope with the demands of other ex-hospital patients stating:

> . . . one friend . . . started coming round, but she started worrying me because she kept saying she'd got a bottle of tablets and she was talking about suicide, and I didn't know what to do about it, so I phoned the hospital, and there is nothing you can do about it, so that's why I like to keep away from it. I know it sounds horrible. I am supportive and understand but there is nothing I can do, so try and keep away from people that haven't, sort of, got better . . . .

Participants who considered themselves to be well did not like using mental health facilities at all. When discussing his use of a local pub, Andrew recounted how he didn't tell others about his mental illness when he stepped into the role of ''normal'':

> I: Well, presumably they don't know that you've had a history of using the health services?

> Andrew: No. I don't think so . . . . Well, you have to forget about it don't you really, and try and lead a normal life.

Here, Andrew felt it was both possible and appropriate to engage in a ''cover up'' of his true status. This may be regarded as a situation of inverse courtesy-stigma. Just as large scale studies have shown that family members believe their relationship with a person with mental illness

should be kept hidden or otherwise be a source of shame (Angermeyer et al., 2003; Phillips et al., 2002) so too in our study we found individuals striving to move away from the courtesy stigma they felt as a consequence of being associated with colleagues with mental illness as described by John: "I wish I'd never got hooked up in it, I wish I'd led a 'normal' life".

Mishler (1999) described how identity is a construct of comparison as we are defined with reference to others. Whilst four people made sustained efforts to integrate into "normal" community life it is unsurprising that they felt their comparative deprivation and social isolation as shown by David and Simon who experienced stigma and rejection. Similar to three other participants, they retreated back into the "illness" community:

> It wasn't till I was just miserable. I had no company around me to make me psychotic or worry about anything. I'd occasionally meet someone else on the road and share a few dog ends, that kind of thing and get a bit emotional sometimes. It was nice when it was over . . . (David)

> I gave it a go [living independently] I tried, but it was too much for me. I succumbed to the demon drink . . . Case management were brilliant, getting me the flat and everything, but it didn't work out . . . (Simon)

The shame of being part of a mental health group also appeared to lead to discriminatory behaviour in the form of social avoidance of fellow stigmatized members. Participants recounted how they "didn't speak to" fellow mental health "service users" when they bumped into each other at public places. Similar to Goffman's thesis individuals who were "getting better" in this study occupied two social realities. On the one hand they were participants in the non-stigmatized world because they did not engage in behaviour which results in labelling but on the other hand, they were members of the social world of the stigmatized since they were related via services to the group. Study participants were denied opportunities to carry out normal "adult" social roles since being a "service user" can lead to the appropriation of childish roles. Thus they carried the burden of the stigmatized "service user" label with its connotations of dependence and lack of autonomy. Whilst individuals had opportunities (e.g., social gathering at a pub) to present themselves as members of the "normal" group, the threat of "exposure" and courtesy-stigma from a fellow member of the stigmatized group frequenting the same social occasion was a real one. Simon and Hamilton (1994) also demonstrated that as individuals felt able to move away from a stigmatized group, and able to define themselves as members of the majority, they tended to stigmatize their previous group as a membership mechanism. For example, James stated:

> . . . I feel a bit, I'm always on the periphery you see in one sense I'm way ahead of the patients.

Others, such as Mary found that they fluctuated in wanting contact from fellow mental health users depending on their health as stated by a professional carer:

> . . . when she's well she finds it all very embarrassing and can't be doing with people like that, when she's not well she like, revels in all them people like that.

The energy expended in "cover ups" could be exhausting since every relationship obliges an exchange of an appropriate amount of intimate facts about self, as evidence of trust and mutual commitment (Goffman, 1962, p. 108). For our individuals, even a fleeting

acquaintance with strangers might constitute a danger where small talk could touch on secret failings.

All our study participants experienced the stigma of their diagnosis and found the process of negotiating and re-negotiating their status in everyday life to be difficult yet the reasons why they wished to continue with their charades was unsurprising. Lee et al. (2005) investigating experience of social stigma of 320 people with schizophrenia found that more than a third received negative comments from employers after their illness was revealed and many indicated that their colleagues attitudes deteriorated after disclosure.

Within this study, attempts to move out of the mental health world were fraught with difficulty. People found their behaviour repeatedly pathologized by "non-users", or that they were discriminated against and mocked. Normal conversations in pubs about their lives were felt impossible without lies, if they were not to be at risk of being *outed* as mentally ill. Sometimes medication was omitted during these periods as it reminded individuals of their status, and decreased their ability to interact like non-users (due to side effects like sleepiness, restlessness or thirst). It is unsurprising that individuals did occasionally abandon the struggle and sought refuge in the mental health world again as described below by Simon and John who ended up going back into hospital:

All the best people get ill . . . (Simon)

I'm not judging women or anything, but if I was working and going out with someone, and then I got ill . . . and they might not want to know. They might leave and go off with someone else if I'm not earning any money. (John)

An identity of recovery – more acceptable to whom?

Some individuals felt that an identity of recovery, characterized by a socially valued role and the ability to reciprocate social support, which was more acceptable to society was within their grasp. The following themes were reported as helping people develop their recovery identity.

Respected by carers rather than dismissed as ill. Participants reported that mental health professionals did at times provide support which enabled a move towards an identity which was not primarily about illness. Three main areas which fit into the "decision-making and feedback" category of social support found by Forrester-Jones and Grant (1997) were mentioned at interview; practical help (including help with police matters); help with illness or feelings of confusion; help with medication issues. These are exemplified in the following quotes:

He [Simon] gets practical things done, like getting my phone connected . . . it's like he's such a friendly guy, he had no attitude about him at all, he's like a mate. I mean I can't relate to people who think they have authority over me. I'm a reasonably intelligent bloke and I may find it hard to cope with day to day things of organising my life but um like I mean I cannot relate to people like case managers or social workers unless I feel they are kind of mates, I just don't relate to this thing about, you know, we are superiors and control you. (David)

Well, when I've been in trouble with the Police and stuff like that he's [social worker] always been very helpful, and when I'm feeling down or confused, he's there. He's as reliable as clockwork and better still. (Tony)

> Jenny (at 73a centre) gives me a lot of support. She talks to me in the office. Sometimes I think people are talking about me. They talk to me about changing my medication but I still think people are talking about me and I get upset. Even when they [staff] tell me people aren't talking about me I know that they're right but I still think it. (Angela)

These quotes highlight how consistency, reliability and respectfulness were important indicators of "being helpful" for participants in this study. Being able to discuss issues in an "office" rather than in a public space was also appreciated. Goffman (1962, p. 12) argues that "routines of social intercourse in established settings allow us to deal with anticipated others". Thus, it may be that "the office" whilst primarily the domain of the paid carer, offered private space where individuals knew they would encounter someone who would listen and talk to them respectfully. Angela clearly thought that staff opinions of her illness were correct, in this case that she wasn't being talked about (and stigmatized) by others. Rather, the thoughts she had were symptomatic of her illness hence a discussion concerning her medication. The corollary to this was if care was not provided in this way, people found it difficult to accept.

Support for autonomy and independence. Help to live an autonomous lifestyle was also relevant to individuals' self-concept of "recovery" as shown in the quote by Roy below.

> . . . Everything was marvellous best arrangement I've made. It was like going back to prison in those other places. (Roy)
>
> A: Oh right. Was it just bed-sits that you lived in?
>
> Roy: I've lived in holiday flats and bed-sits.
>
> A: Yes. Did you prefer that to how you live now or are you happier now?
>
> Roy: Well, gosh there's no fighting here [said regretfully].
>
> A: So do you miss it then, when you lived on your own?
>
> Roy: I do miss it. I have to fight, I could fight again if I had too.

Those in residential care regretted compromising their independence, even though their lives had become more secure. The following residential home owner stated that he tried to provide an environment which allowed for individuals' autonomy:

> I try and give him control over his own life - within this structure it's very important, he doesn't feel that he's being manipulated all the time.

Of the five clients living in residential care, four wanted to live more independently, (albeit with some support) as this would give them "greater financial independence and freedom". However, two clients admitted that living a semi-itinerant lifestyle, or even in independent living had not been sustainable and they had returned to care as exemplified by Tony:

> I gave it a go [living independently] I tried, but it was too much for me. I succumbed to the demon drink. Case management were brilliant, getting me a flat and everything, but it didn't work out. I couldn't cope with the bills and everything.

Acquiring a socially valued role. Goffman (1962) argued that the self-isolate who lacks daily social intercourse with others can become depressed, anxious and suspicious. People here reported that having a role other than ''service user'' provided an excuse for social interaction, as well as much needed self-esteem. In particular, having responsibility for another person without a mental illness was a positive move towards a sense of self-styled recovery: I'm going out with him, I'm a girlfriend, he gives me support and I give him support (Angela). The role of ''girlfriend'' provided Angela with a function which incorporated giving support rather than always being the recipient of it. Whilst stigma is a situation of the individual who is disqualified from full social acceptance (Gecas, 1982), the roles of ''girlfriend'' and ''carer'' enabled individuals like Angela to move towards a more socially acceptable identity. In addition, individuals can control information they give to others much more effectively if they are acting out roles which they can describe and discuss. So, Angela needed only to talk about her roles as girlfriend and carer if she wished to, and was able to manage her stigma in a way which was functional for her own identity. Similarly, for Sarah, the personal identity of ''child-minder'' provided a role and self-concept above and beyond that of ''service user'':

> She [Emily] trusts me with the kids and that gives me a boost. I feel responsible that she is trusting me with these kids, and that I can look after them. But if I got to the stage that I couldn't cope I would tell her and say 'I can't do it today, there's too much pressure at the moment, give me a couple of days and then I'll do it'. I've done that quite a lot of times

In return, Emily stated:

> . . . she wasn't meant to have my kids when I went away, my mum was meant to have them but I fell out with mum and she ended up having all three of them . . . I wouldn't have left my kids with her if I didn't think she was alright at the time. . .

The carer role helped individuals feel useful, less isolated and lonely, boosted their self-esteem and gave a structure to their day and as Angela stated ''. . . it makes us self-reliant and independent of institutions''.

At the same time, the social identity of being mentally ill enabled support to be provided on a flexible basis only, on the understanding that the commitment could be broken on individuals' own terms, according to how ill or fit-for-role they felt. This dual identity (what Goffman (1962, p. 159) called ''stigmatized and normal complementary roles'') was found to usefully co-exist. Nevertheless, apart from financial and practical costs of providing support, participants sometimes felt that helping people who were not ill was often met with suspicion concerning competence. This was reported in four interviews and 2 focus groups. For example, Tina said: ''people are not sure if you are capable of it''. Similarly Sarah, recalling Emily's concern for her health:

> Well sometimes she [Emily] can be a bit over the top. She'll say 'are you alright'? If I don't say yes, if I've got a sore throat or a bad headache and I don't want to come round, she'll say 'I'm not sure you're OK'. If it's nothing else, if it's just a normal sore throat, leave me alone, I'm fine. I just want to say 'I'm not coming out today, you know'.

This quote shows how having a mental illness runs the risk of all acts (even having a sore throat) being open to a pathological interpretation. Social inclusion was also revealed to be

an important stage in developing an identity of recovery. For three clients this meant resuming contact with their partners, children and parents. For three others it meant moving into non-segregated settings without the threat of exposure. For instance, John was an accomplished writer and poet, occasionally reading his work at mainstream social events. This opened up a new life for him where he was accepted, valued and admired and part of his local community (despite his refusal to wash himself, and insistence on talking incessantly). Thus, John found a social network tolerant enough to define him as an ''artist'' rather than a ''mental health case''.

Discussion and conclusion

The literature on deinstitutionalization assumes that individuals move through a ''stepping stone'' process (Deegan, 1996) towards fully integrated services, i.e., moving from total segregation, to segregated day centres, to mainstream community settings (Shepherd, 1984). Case Management aims to accompany individuals on their journey and assumes that support received along the way will become less necessary (Rapp, 1998) as they recover. However, this study revealed a more fluid model of social support (see Figure 1) in operation in which some individuals progressed from one stage to another, whilst others moved around less frequently.

In particular individuals tended to move in and out of mental health networks, an important source of refuge at times of ill health or loneliness despite the instability of the network and the stigma associated with it. At their most vulnerable, individuals were not able to give support to others, and did not receive it from any source except mental health professionals.

During recovery, support from colleagues with similar difficulties and problems was invaluable.

Mental illnesses are characterized by rapid and frequent fluctuations (Burns, 2004, p. 21) and clinical and social needs can rarely be predicted or planned in advance. It is therefore imperative that case management adopts a flexible approach in its co-ordination and delivery of care. Apart from providing general and more specialised mental health interventions (administering medication, assessing side effects, family therapy), Burns (2004) advocates a need for a range of psychosocial and rehabilitative interventions including skills training as well as social supports (e.g. help with obtaining benefits and ensuring adequate physical health care and nutrition). We would add to this the need for support in social skills training and supportive employment, known routes to opportunities for gaining and maintaining social support networks (Forrester-Jones et al., 2004).

Mishler (1999) suggests that identities are not fixed, but are shifting according to roles being played at any one time and obligations to wider communities. Figure 2 shows how identity for the study group tended to shift from ''sick'' and ''stigmatized'' to ''recovery'' whilst individuals made attempts towards establishing another identity for themselves, more acceptable to wider society. This was a stressful pursuit compared to more sheltered lifestyles in institutions, albeit with their own unacceptable privations. Over ambitious attempts to be people for whom mental illness had never occurred (including non-compliance with treatment programmes) led to the personal denial of any other identity. This was the pattern for all the study participants, with half of them seeking excitement and making themselves vulnerable to stress, stigmatization and rejection from others including family, and the other half finding the threat of stigma, courtesy-stigma and rejection leading them to live quite reclusively, suffering from boredom, loneliness, depression leading ultimately to a return to the ''sick identity''.

This raises important issues about how individuals can be supported to live independently, engaging in healthy risk-taking activities as they attempt to rebuild their lives. Space to negotiate identities of choice rather than negative ''sticky'' ones should be at the heart of rehabilitation. As part of this process, Burns stresses the need for case managers to provide or mediate daily/weekly supportive contact with individuals rather than simply providing social support as an added extra once the client is stabilized and living in an adequate environment (Shepherd, 1984). Nevertheless, this study found that the way in which professional care was delivered was perceived at times as instrumental in brokering a descent towards an identity of being ''sick'' and ''stigmatized''. Burns (2004, p. 23) argues that ''person skills'' of staff such as enthusiasm, empathy, compassion, engagement, tolerance and being able to understand the other's point of view are vital to effective treatment programmes. ''Role-blurring'' or as Burns states ''stretching'' or providing aspects of care that are normally regarded as ''unimportant'' or may be just outside the case manager's/key-worker's job description may therefore be needed. For example, providing support to engage in meaningful paid activities which lead to opportunities for developing relationships, could buffer against boredom and loneliness as well as lessoning the need for secondary gains of the ''sick'' identity. These strategies might usefully be incorporated into non-paternalistic individualized treatment plans. Such formal social support needs to be embedded within a multidisciplinary team which provides ongoing professional training and skills and professional development (in e.g., psychology, supportive psychotherapy values, recognition of psychopathology) as well as adequate administrative support to staff.

Participants were also found to be disadvantaged in the construction of valued social roles, as their illness episodes forced them to constantly re-negotiate their identity performances (again, see Figure 2). In the absence of wider opportunities to lead a useful life with a socially validated identity like paid work, individuals needed the chance to give and receive social support which was crucial in helping them develop an acceptable sense of self. For many, this was an opportunity to interact with others in an essentially non-ill way, providing a space of negotiation, but with the implicit acceptance that only other individuals with an association to mental health services could give them. When they felt able, participants began to reciprocate more consistently, and simultaneously re-established networks with friends and family outside of mental health services.

Social support is therefore integral to clinical care whether mental health professionals, friends or family provide it. Whilst people who have the least emotional resources cannot be left to sustain each other indefinitely, clinicians have an important role in providing support for those not able to accept it from anywhere else, e.g., during an initial psychotic episode. Treatment programmes should also incorporate social support for informal carers and families. Mental health professionals also need to work sensitively with individuals, assisting them in their attempts to establish a non-ill identity. Helping people harness social support which can enable them to lead meaningful lives with valued roles, through a sense of reciprocity and social belonging is a crucial treatment modality and to this end we provide seven allied practical recommendations. The question is whether services can rise to the challenge.

(1) When constructing treatment plans, mental health professionals need to draw extensively on individual's existing social networks which may hold the key to building lives of meaning within their own terms. The ways in which supportive social interaction can facilitate recovery and reconstruction of acceptable identities may need to be incorporated into professional training.

(2) User-run social support networks should be mapped, then supported, resourced and respected within the delivery of mental health programmes since they provide

opportunities for reciprocity, which builds self-esteem, self-reliance and develops new skills.

(3) Individual care plans should include supported opportunities for movement out of mental health services into non-segregated life, and assistance for individuals to re-establish non-ill identities.

(4) Psycho-social education programmes should be available to individuals with mental health problems so that they can acquire skills to control their illness and return to everyday life. Their illness would therefore become part of their life, not its defining feature.

(5) Mental health professionals should work sensitively concerning the responsibilities and stresses that occur when people with mental health problems provide social support to others. Assertiveness and communication training for carers with mental health problems should be available.

(6) For some people, mental health services offer a refuge from the stress of life in a discriminatory world and those who want to receive social support in segregated settings need to continue to receive their care in this way.

(7) Rehabilitation programmes should redefine recovery as being a continual process, rather than an end point and should assist individuals to develop and enhance their own social support networks. During periods of ill health, these should not be lost, but left in abeyance until individuals are able to participate in them again. When recovery starts, individuals should not have to start rebuilding networks from scratch.

Notes

1 This paper uses data from an unpublished PhD. The citation is as follows: Barnes, A. (2004). The role of social support in the delivery of mental health programmes for people with severe mental illness living in the community. University of Kent.

2 This section is based on personal experience of providing essential services to homeless people with mental illness during this period. The best-published reference is Hunt and Hemmings (1991).

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